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EDITORIAL

Op Ed Still learning from DES flaws
BEVERLY BECKHAM

Andrea Goldstein tells the story. But it isn't just her story. She speaks for thousands, perhaps millions.

Goldstein is a DES daughter. In the late 1940s, her mother had a healthy son followed by two miscarriages. Then she got pregnant again. In order to have another healthy baby, she was advised by her doctors to take DES (diethylstilbestrol). Over nine months, she took some 725 pills. Then Andrea was born, blonde, blue-eyed and perfect.

In 1971, when Goldstein was 18, the news broke: DES, which was marketed under more than 200 names, was linked with a rare vaginal cancer. The Federal Drug Administration ordered doctors to stop prescribing it to pregnant women. There was a flurry of news stories, a surge of public interest, a rising panic. But the word "rare" stuck to the story and interest waned and panic passed. Vaginal cancer, infertility, abnormalities of the reproductive organs were isolated female problems.

Some 4.8 million pregnant women took DES between 1938 and 1971. They took it because their doctors told them to take it. In fact, DES was supposed to be so beneficial that an ad that ran in a major medical journal in 1957 actually showed a perfect baby next to the promise that DES prevented abortion, miscarriage and premature labor and was "recommended for all routine ... pregnancies." DES was considered such a wonder drug that, unbeknownst to pregnant women, it was often added to their prescribed vitamins.

But DES was never a miracle drug. Researchers knew it caused cancer in lab animals way back in 1938. As early as 1953, doctors at the annual meeting of one gynecology society were told

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that DES not only didn't help pregnancies, it harmed them. DES mothers had higher blood pressure, smaller babies and twice as many miscarriages as mothers who were given placebos.

Still, the drug makers kept producing DES and doctors kept prescribing it for 18 more years.

When Goldstein first read about the effects of DES she was 18. "I thought I was going to die," she says. "I thought, I'm never gonna grow up and marry and have kids." Frightened, she went to her doctor, who assured her that she was perfectly normal and healthy and had nothing to worry about.

So she married and got pregnant, but it was a tubal pregnancy, another condition linked to DES daughters. She lost one fallopian tube, went to an infertility specialist, who discovered that her uterus was deformed (another condition linked to DES daughters), got pregnant again, miscarried, then had another tubal pregnancy, which resulted in the loss of her second fallopian tube and the loss, at 26, of all hope of ever having a baby.

"It was the one thing I wanted to do," she says now. "I wanted children. We adopted one but then the price of adoption went so high."

Goldstein has been gathering and disseminating information about DES since she first read about its effects 25 years ago.

"Ninety-five percent of DES daughters have benign abnormalities of the reproductive system. At least one-third of DES sons have testicle abnormalities. DES children are now reaching their 40's. Will they have a higher incidence of breast cancer? Will DES sons be more prone to prostate cancer. And what about their children? These are things we need to know."

In 1992, the federal government finally passed legislation to fund a national DES research and education program. Mothers who think they may have been given DES and men and women who think they were exposed, should call 1-800-DES-NEWS. "There's a lot to be learned from us," Goldstein says.

The essential thing to be learned is caution. Women desperate for babies continue to take desperate measures. The lesson of DES is that women must never stop asking questions and

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demanding answers.

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